

Prostate Cancer Screening and Informed Decision Making

The goal for prostate cancer in the Washington State Comprehensive Cancer Control Plan is to improve informed decision making between men and their providers regarding prostate cancer screening.¹ This literature review provides an overview of informed decision making as it relates to prostate cancer screening. First, we define informed decision making (IDM) and shared decision making (SDM). Second, we summarize the literature identifying the facts about prostate cancer screening that men need to know in order to make an informed decision about screening. Third, we address the question of whether men are making informed decisions about prostate cancer screening in the absence of IDM interventions. Finally, we review what is known about the effectiveness of IDM interventions for prostate cancer screening decisions.

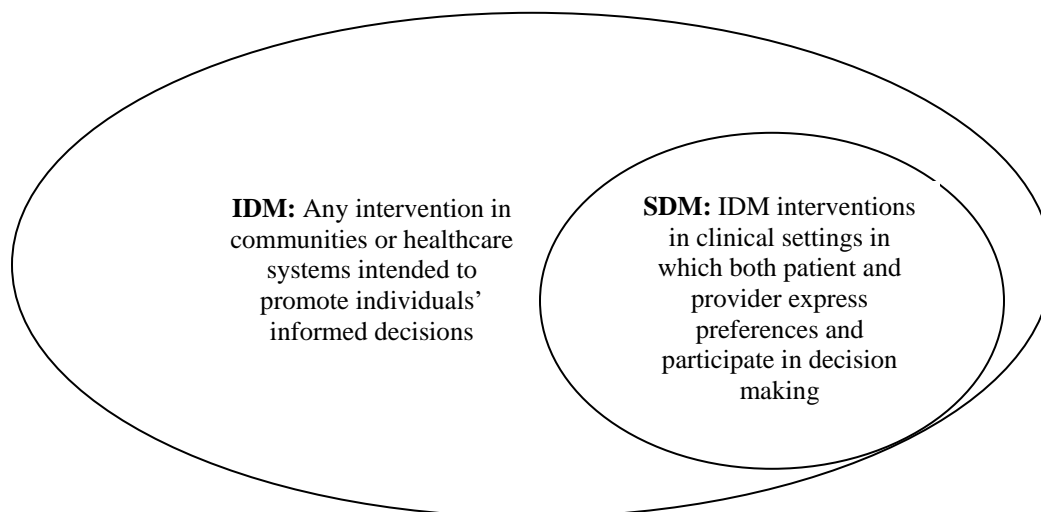
Definitions of Informed Decision Making and Shared Decision Making

Informed decision making and shared decision making represent departures from the paternalistic model of health care in which the doctor tells the patient what to do. According to the Institute of Medicine, quality health care is respectful of and responsive to the patient's needs and values.² IDM and SDM are approaches to decision making that take patient needs and values into account.

IDM occurs when an individual:

- Understands the nature of the disease or condition
- Understands the clinical service being offered and its risks, limitations, benefits, alternatives, and uncertainties
- Has considered his or her preferences about the clinical service
- Has participated in decision making at the level he or she desires
- Makes a decision consistent with his or her preferences or chooses to make a decision at a later time³

SDM occurs when a patient and his/her doctor both express preferences and participate in making decisions about clinical services in the clinical setting.³ Another way of understanding IDM, SDM, and how they relate to one another is shown in the figure below, adapted from Briss and colleagues.³



What do Men Need to Know to Make an Informed Decision About Prostate Cancer Screening?

The clinical practice guidelines for several professional organizations (including the American Cancer Society and the American Urological Association) recommend that men make an informed decision about prostate cancer screening with their doctors. However, there is very little guidance on what information is required for men to make an informed decision. Chan and Sulmasy⁴ recruited a panel of national experts in prostate cancer, which included urologists, family physicians, oncologists, and internists. These experts were asked “What should men know about PSA screening before giving informed consent?” In the same study, Chan and Sulmasy also conducted focus groups of couples to see what men and their wives thought was crucial information about prostate cancer screening (the focus groups included both screened and unscreened men). At the end of this study, the following information was proposed as sufficient for men to provide informed consent. The “basic minimum” list takes into account the fact that doctor visits are usually short, and were agreed on by the experts and couples as the most crucial information. The “conversation with physician” and “brochure” information reflects information to be disclosed under ideal circumstances.

Basic Minimum

1. False positive prostate-specific antigen test results can occur.
2. False negative PSA test results and false negative biopsies of the prostate can occur.
3. Nobody knows whether regular PSA screening will reduce the number of deaths from prostate cancer.

Conversation with Physician

1. The PSA test is a blood test for prostate cancer.
2. Done together, the digital rectal examination and the PSA test can screen for prostate cancer.
3. The PSA screening test can detect prostate cancer sooner than digital rectal examination alone.
4. An elevated PSA test result may lead to other tests to see whether prostate cancer is present.
5. The risk of getting prostate cancer is higher in a man who is older, has a family history of prostate cancer, or is African American.
6. Prostate cancer may grow slowly and not cause any symptoms. That is why prostate cancer may not kill older men. They may outlive this cancer and die from something else.
7. A man over age 70 is less likely to die from prostate cancer even though he is at higher risk to have it.

Brochure

1. The PSA screening test is controversial.
2. There are advantages and disadvantages to taking the PSA test. One disadvantage is that a man could end up worrying about what an elevated PSA test result means.
3. Done together, the PSA and digital rectal examination are most appropriate for men who have more than 10 years left to live.

4. A man with early prostate cancer can choose watchful waiting, radical prostatectomy, or radiation therapy.
5. There are side effects from prostate cancer treatment such as impotence, incontinence, narrowing of the urethra (strictures), trouble urinating, and rectal scarring.
6. Nobody knows whether treating prostate cancer early is helpful or whether one treatment is better than another.
7. Although a man thinking about taking the PSA test can consult a doctor, he should make the final decision himself.

Are Men Making Informed Decisions?

Most national surveys of health behavior that assess prostate cancer screening only ask men whether or not they have been screened for prostate cancer screening, so there is limited data about whether men make informed decisions about prostate cancer screening. The studies we do have suggest there is a lot of variation in IDM and SDM practices for prostate cancer screening, with some men making informed decisions and other men not. In a recent study, one-third of men asked whether they had received a PSA test during their clinic visit incorrectly replied “no.”⁵ In other words, one-third of the men in the study sample were not aware that they had been given a PSA test during their doctor visit, which implies that they did not make an informed decision to be screened.

In a national survey, 66% of the men who reported that they had been screened with PSA said that their doctors had discussed the advantages and disadvantages of the test before the PSA was given.⁶ Similarly, the majority of doctors who completed the Alliance for Reducing Cancer Northwest’s (ARCNW) physician survey reported “always or almost always” discussing the risks and benefits of PSA screening with patients (74%; 52% of the doctors said that they always or almost always discuss risks and benefits of digital rectal examination). Few studies have measured men’s informed decisions rates, so there is still a lot we don’t know about IDM and prostate cancer screening in everyday medical practice. Several researchers have designed interventions to promote IDM for prostate cancer screening. We conclude this report with a review of the effectiveness of these interventions.

Are Prostate Cancer Screening IDM Interventions Effective?

Briss and colleagues’ review of IDM interventions³ concluded that there is good evidence that IDM interventions:

- Improve people’s knowledge about the disease
- Improve accuracy of risk perceptions
- Increase knowledge and influence beliefs about the pros and cons of screening choices

Most of the studies in this review were evaluating prostate cancer screening IDM interventions.³ Prostate cancer screening IDM interventions conducted since this review have generally shown similar benefits in improving men’s knowledge about prostate cancer, risk perceptions, and understanding the pros and cons of screening.⁷⁻¹⁰

Relatively few studies have assessed whether IDM interventions help people:

- Participate in making a decision at a level they’re comfortable with
- Make a decision consistent with their values and preferences

Therefore, it is unclear whether or not IDM interventions meet all of their goals.³ One later study found that men who participated in an IDM intervention had lower levels of decisional conflict than the control group.⁹ Another study found no difference in satisfaction with the screening decision between men who received an IDM intervention and men who did not – but satisfaction was measured a year after the intervention took place.⁷ Future studies of prostate cancer screening IDM interventions should include similar measurements of men's satisfaction with their participation in the decision-making process and the screening decision.

In spite of the unknowns about IDM interventions, the Task Force of the Community Guide to Preventive Services identifies prostate cancer screening as a high-priority issue for IDM interventions.³ The issues surrounding prostate cancer screening are complex and most clinical guidelines recommend that men make an informed decision with their doctor about whether or not to be screened.

References

1. *Washington State Comprehensive Cancer Control Plan 2004-2008*. Olympia, WA: Washington State Comprehensive Cancer Control Partnership; 2003.
2. *Crossing the quality chasm: a new health system for the 21st century*. Washington DC: National Academy Press: Institute of Medicine; 2001.
3. Briss P, Rimer B, Reilley B, et al. Promoting informed decisions about cancer screening in communities and healthcare systems. *Am J Prev Med*. Jan 2004;26(1):67-80.
4. Chan EC, Sulmasy DP. What should men know about prostate-specific antigen screening before giving informed consent? *Am J Med*. Oct 1998;105(4):266-274.
5. Chan EC, Vernon SW, Ahn C, Greisinger A. Do men know that they have had a prostate-specific antigen test? Accuracy of self-reports of testing at 2 sites. *Am J Public Health*. Aug 2004;94(8):1336-1338.
6. Lu-Yao G, Stukel TA, Yao SL. Prostate-specific antigen screening in elderly men. *J Natl Cancer Inst*. Dec 3 2003;95(23):1792-1797.
7. Volk RJ, Spann SJ, Cass AR, Hawley ST. Patient education for informed decision making about prostate cancer screening: a randomized controlled trial with 1-year follow-up. *Ann Fam Med*. May-Jun 2003;1(1):22-28.
8. Partin MR, Nelson D, Radosevich D, et al. Randomized trial examining the effect of two prostate cancer screening educational interventions on patient knowledge, preferences, and behaviors. *J Gen Intern Med*. Aug 2004;19(8):835-842.
9. Gattellari M, Ward JE. Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomised controlled trial. *J Med Screen*. 2003;10(1):27-39.
10. Bridge PD, Berry-Bobovski LC, Gallagher RE. Promoting informed decision making: evaluating a community-based prostate health awareness program. *J Cancer Educ*. Fall 2004;19(3):174-179.

Prepared by:

Peggy Hannon, PhD, MPH

Alliance for Reducing Cancer, Northwest

University of Washington Health Promotion Research Center

May 2005